

## Service Delivery Experiences and Intervention Needs of Military Families with Children with ASD

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Davis, J., Finke, E., & Hickerson, B. (2016). Service delivery experiences and intervention needs of military families with children with ASD. *Journal of Autism and Developmental Disorders*, 46(5), 1748-1761. doi:10.1007/s10803-016-2706-8

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### Abstract:

The purpose of this study was to describe the experiences of military families with children with autism spectrum disorder (ASD) specifically as it relates to relocation. Online survey methodology was used to gather information from military spouses with children with ASD. The finalized dataset included 189 cases. Descriptive statistics and frequency analyses were used to examine participant demographics and service delivery questions. Results indicated the larger sample of military spouses largely confirmed the experiences reported qualitatively in previous studies and contributed information that was previously unknown about variables associated with the access, availability, quality, and frequency of intervention services for military families with children with ASD.

**Keywords:** Autism | Military families | Service delivery | Survey

### Article:

#### Introduction

Few peer-reviewed articles have investigated the experiences of military families with children with ASD; however, previous research has suggested recurring issues with intervention services as a result of relocation to a new installation (Davis and Finke 2015). The goal of this project was to better describe the service delivery challenges and intervention needs of military families and their children with ASD related to relocation in a larger sample of military spouses. While difficulties with intervention and service availability are not limited to military families, military families may be at additional risk because of the frequency of relocations and need to re-establish services.

#### Literature Review

Autism spectrum disorder (ASD) is a developmental disability characterized by deficits in social interaction, communication, and behavior (APA 2013). For an individual to receive a diagnosis of ASD, he/she must present with a series of symptoms in the categories of social communication and interaction in addition to restricted and repetitive behavior (APA 2013). According to the Center for Disease Control, ASD has been on the rise over the past several decades and currently affects approximately 1:68 children and 1:44 males (ADDNM 2014). Although individuals with ASD generally improve with maturation and intervention services, some impairments are lifelong (Howlin et al. 2000; Seltzer et al. 2003).

Due to the range of impairments associated with ASD (e.g., Barbaro and Dissanayake 2009; Matson et al. 2009; Rogers and Ozonoff 2005), intervention plans often comprise a wide range of services. Treatment may include behavioral interventions, pharmaceutical management, dietary restrictions, dietary supplements, and/or educational programming. Many specific intervention techniques are encompassed in each broad intervention class. For example, a report by the National Autism Center (2015) investigated the effectiveness of 389 peer-reviewed studies creating 45 behavioral and educational intervention categories for individuals with ASD. Within the “established” or highest level of evidence category, there were 14 different treatments for individuals under the age of 22 years (NAC 2015). Further, a survey of medical interventions for individuals with ASD found at least 15 different medications available for families and physicians to choose from (Aman et al. 2005) which often offer marginal benefits in treating core symptoms, hyperactivity, aggression, or restrictive and repetitive behaviors (Huffman et al. 2011). With the variety of options available, families and providers are confronted with a daunting task when planning intervention for individuals with ASD.

Aside from deciding which interventions to pursue, families with children with ASD must find and coordinate services and interact with a number of professionals from different backgrounds and disciplines. Kohler (1999) reported families with children with ASD between the ages of 3–9 received an average of 6.44 services and worked with an average of 7.7 professionals over a period of 6 months. More recent research has corroborated these findings. Surveys by Goin-Kochel et al. (2007) and Green et al. (2006) found parents of children with ASD reported using 4–7 different interventions at one time. However, coordinating and working with several professionals is only part of the challenge facing parents of children with ASD.

Families of children with ASD consistently report challenges with intervention and service delivery, including difficulty obtaining services (Kohler 1999; Sperry et al. 1999), limited availability and accessibility of services (Kohler 1999; Little 2003; Montes et al. 2009; Vohra et al. 2014), and dissatisfaction with quality of services (Montes et al. 2009). Kohler (1999) surveyed parents of children with ASD and found all families identified at least one issue with service delivery ranging from delays in accessing intervention to challenges with payment for services received. Vohra et al. (2014) analyzed data from the 2009–2010 National Survey of Children with Special Health Care Needs and concluded parents of children with ASD were significantly more likely to indicate limited collaboration and decision making, problems accessing services, and lack of service availability than parents of children with other developmental disabilities or mental health conditions. Parents of children with ASD not only reported greater difficulty accessing services, but also greater dissatisfaction with both school

and community related services than parents of children with other developmental disabilities (Montes et al. 2009).

As a result of the intervention and service delivery limitations described by parents, there are unmet therapeutic needs of children with ASD. Farmer et al. (2014) found 98.9 % of parents of children with ASD reported at least one service need. Further, 63 % reported at least one specialty care need (e.g., speech therapy; Farmer et al. 2014). The most common service needs for children with ASD reported by parents were behavioral therapy (65 %), communication aids/devices (52.4 %), occupational/physical therapy (46.1 %), and speech therapy (41.5 %; Farmer et al. 2014). Sixty-four percent of parents also reported at least one family need related to genetic counseling (70.5 %), respite care (70.1 %) and/or family mental health (63 %; Farmer et al. 2014). Murphy and Ruble (2012) asked parents of children with ASD (who lived in metropolitan and non-metropolitan areas) to prioritize a list of services based on need. The needs of each group were similar with both metropolitan and non-metropolitan parents ranking social skills training, speech-language therapy, and behavior management as part of their top four needs (Murphy and Ruble 2012). While service delivery issues and unmet needs are common for many parents in a variety of different life circumstances, a subset of the ASD population may be at even greater risk for these challenges and needs—military families.

## **Military Families**

Military families are characterized by a constellation of experiences, separating them from families with caregivers working in other occupations (Segal 1986). Military families must cope with family separation for training or deployment, frequent relocation, living overseas, and dangerous work environments (Segal 1986). Though all pose challenges for military families, one experience may particularly and uniquely affect military families with children with ASD in terms of intervention and service delivery is relocation.

Military families relocate approximately three times more often than civilian families (Drummet et al. 2003). Children in military families switch schools an average of 6–9 times from grades K-12 (Ohio State University Project Team 2011b). Relocation requires the military family to adjust to the new location and lifestyle, develop new routines, and establish new community relationships (Drummet et al. 2003). Geographic mobility has also been shown to affect the socioemotional well-being of military children (Burrell et al. 2006) and cause disruptions in their educational programming (Aronson et al. 2011). These disruptions may be especially harmful for military children with special needs who likely require more interventions and specialized school services than their peers who are neurotypical.

There is currently little information about military children in general (Macdermid-Wadsworth 2013), and even less about military children with special needs. A few peer reviewed articles (e.g., Davis and Finke 2015; Jagger and Lederer 2014) in addition to some government and organization reports (e.g., NCD 2011; Ohio State University Project Team 2011a,) have suggested difficulties may be associated with acquisition and maintenance of special needs services during relocation. Military spouses with children with special needs, including ASD, reported challenges in the following areas after relocation: interrupted school and special education services, difficulty finding providers and accessing services, difficulty obtaining

comparable services, lack of continuity of services, and delays/gaps in service (Ohio State University Project Team 2011a; Davis and Finke 2015; Jagger and Lederer 2014; NCD 2011). To help counteract stressors related to relocation, the military has developed some supports for military families, including those with special needs. The Interstate Compact on the Educational Opportunity for Military Children is legislation to “remove barriers to education success imposed on children of military families because of frequent moves and deployment of their parents” (MICCC 2011). Specifically, some of the barriers the Compact strives to address are enrollment, placement, eligibility, and graduation (MICCC 2011). All fifty states have signed the Compact as of 2015 (MICCC 2015). Another support currently in place is the school liaison program, which seeks to connect military commanders, military families, and schools to facilitate military-school related issues (DoDEA 2014). Each military branch operates its own school liaison program to accommodate branch specific differences (Aronson et al. 2011). A program specific for military family members with special needs is the Exceptional Family Member Program (EFMP). Similar to the school liaison program, each military branch staffs and organizes their own version of EFMP to document and provide case management for family members with special needs (OAR 2010). EFMP also attempts to relocate military families to areas where the services required by the special needs family member are available (Braisure et al. 2012). The EFMP programs also may “provide a range of direct support for families with special needs,” but this function is not required, and may vary by branch and location (OAR2010). The supports that are currently in place, though a good start, may not be enough to address all of the needs for military families with children with ASD, as many of these families report problems with therapeutic service delivery (Davis and Finke 2015).

## **Current Study**

Much of the current evidence on the challenges for military families with children with ASD comes from military and organization reports, which are not peer-reviewed. To date, there have been two peer-reviewed, empirical investigations exploring the experiences of this specific population. One previous study used semi-structured interviews to determine the experiences of military spouses with a child with ASD and reported military families with children with ASD have difficulties with many aspects of service delivery (Davis and Finke 2015). However, these results were from a limited sample of military spouses ( $n = 15$ ) and there is little previous evidence to corroborate these findings. To better understand the relationships between services for military families with children with ASD and relocation, additional research should be completed. The purpose of this study was to use a broader reaching research methodology (i.e., online survey) to better describe service delivery experiences and intervention needs related to relocation in a larger sample of military spouses with children with ASD. Specifically, the research questions for this investigation were: (1) what are service delivery experiences of military families with children with ASD? and (2) what are the intervention and service needs of military families with children with ASD?

## **Methods**

### **Design**

To determine the service delivery experiences and intervention needs of a larger sample of military families with children with ASD, a self-administered online survey design was chosen. Surveys allow researchers to generalize findings from a small population to a larger one in a time and cost efficient manner (Rea and Parker 2005). Additionally, surveys are appropriate when the data are self-reported and based on the respondents personal experiences (Rea and Parker 2005). An online delivery mode was utilized to extend the “reach” of the survey and collect data from respondents who may live in a number of geographic regions (Van Selm and Jankowski 2006). Military families may be located anywhere in the United States, including Alaska and Hawaii, or in installations overseas, encompassing three continents (Military Community and Family Policy 2013). Online surveys limit interviewer bias and data entry error while allowing for easy follow-up and quick data collection (Rea and Parker 2005; van Selm and Jankowski 2006).

### **Sample Strategy**

Nonprobability sampling procedures were used for this survey. Nonprobability samples are appropriate when probability samples are not feasible and when the goal is to target members of a specific population (Rea and Parker 2005). Specifically, purposive nonprobability sampling was used, which allowed the researcher to set inclusion criteria based on the characteristics of interest for respondents (Rea and Parker 2005). Additionally, snowball sampling was utilized to inform more members of the population of the survey (Rea and Parker 2005). When the survey was distributed, military families and organizations were asked to share the survey with others who met the inclusion criteria.

### **Inclusion Criteria**

Inclusion criteria were established to locate respondents who had characteristics relevant to the research question (Creswell 1998). To participate in the study, an individual needed to: (1) be the spouse or partner of an active duty service member of the Air Force, Army, Coast Guard, Marine Corps, or Navy; (2) be a parent/caregiver of a child with special needs whose child is between the ages of 4–21; (3) be at least 18 years old; (4) be fluent in English; (5) have access to internet; and (6) consent to participate in the study. Participants who did not meet all inclusion criteria were not eligible to complete the survey. The survey was designed to screen respondents on relevant characteristics to determine which respondents matched the criteria (van Selm and Jankowski 2006). For this investigation, an additional criterion was established to delimit the sample to only military families with a child with a primary diagnosis of ASD. If respondents reported a diagnosis of a disability other than ASD (e.g., visual impairment) or a dual diagnosis of ASD and another primary diagnosis (i.e., Down’s syndrome, cerebral palsy) for their child, their responses were excluded from the analysis in this paper.

### **Survey Development**

The questions and responses in this survey were generated based on a review of the literature on families of children with ASD and/or other disabilities (e.g., Renty and Roeyers 2006; Stoner et al. 2005; Kohler 1999), military families (e.g., Huebner et al. 2010; Blue Star Families 2013; NCD 2011), and military families with children with ASD (Davis and Finke 2015). In addition to questions developed by the researchers, questions from other studies were included. Montes,

Halterman, and Magyar (2009) used statements with yes/no responses to determine the satisfaction of parents of children with ASD regarding therapeutic services. Murphy and Ruble (2012) asked parents to rank common services children with ASD and/or families of children with ASD receive based on the respondents' current level of need. Statements from Montes et al. (2009) as well as the list of services in Murphy and Ruble (2012) were adapted and included in the survey.

All specific questions and responses were created following best practices in survey question design to increase participation and decrease dropout (e.g., Rea and Parker 2005). Questions were written as concise, simple, and neutral as possible and asked about one experience at a time (Rea and Parker 2005). Responses were presented in a logical order (e.g., alphabetical; Rea and Parker 2005). When appropriate, an additional response of "Other; please specify" was included to capture information not accounted for in the provided survey responses (Rea and Parker 2005). Open ended questions increase burden on respondents; therefore, these were used sparingly and strategically throughout the survey (Rea and Parker 2005). The survey instrument contained 98 items in seven categories of questions. Only questions about service delivery and therapeutic needs were analyzed in this paper.

Prior to distribution, the survey was piloted with members from the target population. Specifically, an email explaining the study, instructions for the respondents, and the survey link was sent to the fifteen military spouses with a child with ASD who participated in the interview study reported in Davis and Finke (2015) as well as three other military spouses with a child with special needs familiar with the researcher. Since these spouses have previous rapport with the researcher, they may have been more willing to spend time analyzing the survey and providing honest feedback on the clarity, comprehensiveness, and acceptability of the questions in the survey. The survey was changed and updated to address the suggestions made by the military spouses who responded to the pilot.

## **Survey Distribution**

The final version of the survey was distributed in three ways. First, recruitment materials were posted on social media websites relevant to the target population. Military family groups (e.g., American Military Families Autism Support), and special needs groups and organizations (e.g., Autism Speaks; Special Olympics) were contacted and given information about the survey and survey purposes. Moderators were asked if they would post a recruitment message on the group website/page or allow the researcher to post a recruitment message. If the group was a public group and/or did not have a moderator, the researcher posted the recruitment message. Recruiting via social media is an appropriate strategy as many military families report using social media networking sites. In a survey conducted by Blue Star Families (2013), 89 % of military spouses reported using Facebook everyday and 99 % reported using it at least a few times per month. Additionally, previous studies have recruited similar populations using this method (e.g., Davis and Finke 2015; Mackintosh et al. 2012). Second, some individuals or groups who read the recruitment materials shared the recruitment message with other groups and families by utilizing information diffusion functions on social media platforms (e.g., "share" on Facebook; "retweet" on Twitter). Third, military spouses who responded to recruitment materials from Davis and Finke (2015) who agreed to allow researchers to keep their contact information

were sent recruitment materials via email. Military spouses who responded to the pilot invitation were not included in this round of recruitment. Contacts with the groups and military spouses followed a web-based version of Dillman's Tailored Design Method (Dillman et al. 2009). For example, the initial contact contained information about sponsorship, information about the survey, and reassurance of confidentiality (Dillman et al. 2009). Distribution and recruitment continued for 3 months.

## **Procedure**

Prior to the initiation of any research activities, the University's Office of Research Protections approved the method and materials for this study. After IRB approval, recruitment messages were posted on relevant social media groups and emails were sent to previous research participants. Individuals interested in the survey clicked on the link provided in the recruitment announcement to access the survey in Qualtrics®, an online survey software program. Individuals were informed of the purpose of the survey and their rights as research participants. If the individual consented to participate, he/she was provided access to the survey, beginning with the demographic information section. Three questions in the demographic information section were screening questions that determined the eligibility of the respondent to complete the survey based on specific characteristics of interest. If the respondent met the specific characteristics, they continued to the next section of the survey. If they did not meet the inclusion criteria, the survey ended. For example, if a respondent indicated they did not have a child with special needs, the survey automatically skipped to the end and thanked the respondent for his/her participation. Respondents had the opportunity to leave the survey at any time for any reason and skip any question they preferred not to answer. Additionally, respondents could exit and return to the survey, provided they accessed the survey link on the same computer and web browser. Although all responses were anonymous, respondents had the opportunity to provide their email address if they wished to be contacted about future research opportunities. Respondents who provided an email address, but did not complete the survey were contacted 2–4 times, 2–3 weeks apart regarding completing the survey. Due to the nature of nonprobability sampling, a response rate could not be calculated.

## **Data Analysis**

After data collection, the data were cleaned and checked for outliers. Descriptive statistics were used to describe response distributions for demographic and service delivery questions. Data analysis for this study was completed using SPSS version 22®, a statistical analysis program.

## **Results**

Throughout the 3-month data collection period, 692 people began the survey and 485 met all of the inclusion criteria. This investigation used a subset of the data—only military spouses with children with ASD who did not report a concomitant primary diagnosis of cerebral palsy or Down syndrome were included. In total, 258 responses from military spouses with children with ASD were received. Twelve out of the 258 total responses were military spouses who reported their child was diagnosed with either cerebral palsy ( $N = 8$ ) or Down syndrome ( $N = 4$ ) in addition to ASD and were removed from the analysis. Of the remaining 246, 57 dropped out of

the survey prior to the service delivery questions and; therefore, were not included in this paper. The final sample included 189 military spouses with children with ASD.

### **Demographic Information**

Respondents were military spouses between the ages of 24–55 ( $M = 37.26$ ,  $SD = 5.83$ ). The majority of the military spouses was female (95.7 %), non-Hispanic/Latino (88.4 %), Caucasian/White (90.8 %), had some level of college education (96.8 %), and were stay at home parents/caregivers (66.1 %). Active duty service members were reported to have served a range of 1–30 years ( $M = 15.31$  years,  $SD = 6.19$ ) in either the Air Force (15.3 %), Army (47.1 %), Coast Guard (5.3 %), Marine Corps (7.9 %) or Navy (24.3 %) as enlisted (59.9 %) or officer (40.1 %) ranks. Most of the families lived in either southern (57.8 %) or western (27.6 %) states at the time of the survey, but all regions listed in the US Census 2010 and two countries overseas were represented. The families in this sample reported experiencing between 2 and 11 relocations since the birth of their oldest child with ASD ( $M = 4.02$ ,  $SD = 1.66$ ). Military families reported having 2 or more children (87.7 %) with 1 (68.3 %) or 2 (24.3 %) of those children also having special needs, including but not limited to ASD. The oldest children with ASD in the family were between the ages of 4–21 ( $M = 9.78$  years,  $SD = 4.13$ ) and mostly male (75.7 %), non-Hispanic/Latino (83.2 %), and Caucasian/White (87.6 %). These children were diagnosed with Autistic Disorder (49.2 %), Asperger’s Syndrome (28.6 %), or PDDNOS (21.9 %) and displayed mild (39.5 %), moderate (47.6 %), and severe (13.0 %) levels of ASD symptoms.

### **Service Delivery Experiences**

Military spouses were asked to respond to 11 forced choice questions about their overall experiences obtaining and maintaining interventions for their oldest child with ASD after relocations. Instructions provided to the respondents asked them to answer the 11 forced choice questions considering all of their relocation experiences since the birth of their oldest child with ASD. Therefore, it is not possible to determine the specific installation the military spouses were basing these responses on. Eight of the questions offered two possible choices, the remaining three offered three choices. The service delivery variables investigated in this study were categorized into four groups: access, availability, quality, and frequency. More information about specific wording and categorization is provided in Table 1.



**Table 1** Service delivery experiences

Category	Item	Responses	Frequency	Percentage
Access	Level of access	I have had access to all of the interventions/services my child requires	54	28.7
		I have had access to some of the interventions/services my child requires	118	62.8
		I have had access to none of the interventions/services my child requires	16	8.5
		Total	188	
	Speed of access	I have had timely access to the interventions/services my child requires	40	21.4
		I have had delayed access to the interventions/services my child requires	147	78.6
		Total	189	
	Access to assistive technology services	My child has had access to the assistive technology devices and services that my child requires	31	38.3
		My child has not had access to the assistive technology devices and services that my child requires	50	61.7
		Total	81	
Availability	Finding medical interventions	Finding physicians or medical professionals in my area of the state who are trained in treating my child's disability has not been a problem for me	75	41.4
		Finding physicians or medical professionals in my area of the state who are trained in treating my child's disability has been a problem for me	106	58.6
		Total	181	
	Finding providers who take Tricare	Finding intervention/services providers who take Tricare has not been a problem for me	91	50.6
		Finding intervention/services providers who take Tricare has been a problem for me	89	49.4
		Total	180	
	Proximity of providers who take Tricare	Intervention/service providers who take Tricare are close to my home	82	45.6
		Intervention/service providers who take Tricare are not close to my home	98	54.4
		Total	180	
Quality	Continuity of interventions	The continuity of interventions/services for my child between locations has been adequate	55	30.6
		The continuity of interventions/services for my child between locations has been inadequate	125	69.4
		Total	180	
	Continuity of IEP/504 plans	I am satisfied with the continuity of my child's IEP or 504 Plan between locations	74	45.6
		I am not satisfied with the continuity of my child's IEP or 504 Plan between locations	88	54.4
		Total	162	
	Progress	My child had timely progress after starting interventions/services in the new location	68	37.0
		My child had delayed progress after starting interventions/services in the new location	116	63.0
		Total	184	
	Quality of interventions	I am satisfied with the quality of interventions/services for my child provided by the school	87	48.6
		I am not satisfied with the quality of interventions/services for my child provided by the school	92	51.4
		Total	179	
Frequency	Frequency of interventions	I am satisfied with the frequency of interventions/services provided to my child	77	42.8
		I am not satisfied with the frequency of interventions/services provided to my child	103	57.2
		Total	180	

## Access

The access category contained three variables related to the family's ability to access intervention and services for their child with ASD. The following service delivery characteristics were used to create the access category: level of access to intervention, speed of access to intervention, and access to assistive technology services.

Most military spouses reported problems accessing the services they felt their child with ASD needed. The most frequently reported service delivery experience was delayed access to intervention following relocation with 78.6 % of military spouses reporting these gaps in service. Similarly, almost 63 % of respondents indicated their family only had access to some of the interventions their child required. When a child was in need of assistive technology, 61.7 % reported they did not have access to what they felt was needed for their child. These results indicated the military spouses in this sample had difficulty obtaining interventions their child needed and the onset of intervention was frequently delayed.

### **Availability**

Availability of interventions upon relocation was determined by respondents' answers to three service delivery questions. The items used to create the availability category included finding medical interventions, finding providers who take Tricare, and proximity of providers who take Tricare.

Military spouses experienced challenges related to the availability of intervention providers. Many of the respondents (58.6 %) indicated finding physicians or medical professionals who were trained in treating their child's disability had been a problem. Just under half (49.4 %) of military spouses reported difficulty finding providers who took Tricare near the family was a problem for them. Intervention/service providers who took Tricare were more likely to be reported as not close to the family's home (54.4 %) than close to the family's home (45.6 %).

### **Quality**

This category described the military parents' perceptions of the quality of the interventions and services their child with ASD received following relocation. The following four service delivery characteristics were used to create the quality category: continuity of interventions, continuity of IEP/504 plans, progress, and quality of school interventions.

Military spouses frequently reported the quality of interventions and services to be lacking. Most respondents (69.4 %) reported feeling the continuity of interventions between locations was inadequate. Similarly, 54.4 % of military spouses indicated they were dissatisfied with the continuity of their child's IEP/504 between locations. Possibly related to the respondents' dissatisfaction with continuity of IEPs, many spouses also reported not being satisfied with the quality of interventions/services provided by the school (51.4 %). Another indicator of the military spouses' perception of the quality of interventions and services was their child's progress. The majority of respondents (63 %) felt their child had delayed progress after starting interventions and services in the new location following a move.

### **Frequency**

The frequency category examined military spouses' satisfaction with the frequency of the intervention services their child with ASD received. Many military spouses (57.2 %) indicated dissatisfaction with the frequency of interventions and services provided to their child after relocation.

### **Intervention and Service Needs**

Military family's needs for specific interventions and services were assessed. Military spouses were asked to indicate their level of need (i.e., no need, low need, medium need, high need) for specific interventions and services for their child and for their family. The list of interventions and services was adapted from a list provided to parents of children with ASD in a survey by Murphy and Ruble (2012).

### **Military Child with ASD Needs**

All respondents indicated their child with ASD had at least one intervention need with over 97 % of military spouses in this survey reporting their child had at least one medium level need for one or more interventions. Respondents indicated needing a range of 1–10 of the interventions listed ( $M = 5.84$ ,  $SD = 1.84$ ) for their oldest child with ASD. The most frequent need expressed was for social skills therapy (88.3 %). Followed by behavioral management intervention (78.8 %), speech-language therapy (64.9 %) and physical or occupational therapy (55.6 %). Although inpatient hospitalization/residential services were not utilized as often as other services, these may be critically important for mental health and safety. Over 6 % of military spouses reported at least a medium need for inpatient hospitalization/residential services for their child with ASD. Military spouses also had an opportunity to add any intervention and service need that was not already included on the list. Other interventions and services reported as at least a medium level of need by respondents included sensory therapy, vision therapy, music therapy, audiology, and nutrition. Additional information is provided in Table 2.

**Table 2** Military child with ASD needs

Item	Category	Frequency	Percentage
Behavioral management	No/low need	38	21.2
	Medium/high need	141	78.8
	Total	189	
Individual counseling	No/low need	101	57
	Medium/high need	76	43
	Total	189	
In-home therapeutic support	No/low need	94	52.5
	Medium/high need	85	47.5
	Total	179	
Inpatient hospitalization/residential	No/low need	168	93.9
	Medium/high need	11	6.1
	Total	179	
Medical management	No/low need	108	60.3
	Medium/high need	71	39.7
	Total	179	
PT/OT	No/low need	79	44.4
	Medium/high need	99	55.6
	Total	178	
SLP	No/low need	63	35.2
	Medium/high need	116	64.9
	Total		
Social skills therapy	No/low need	21	11.7
	Medium/high need	158	88.3
	Total	179	
Supplement management	No/low need	136	80
	Medium/high need	34	20
	Total	170	
Other: sensory therapy	Medium/high need	1	
Other: vision therapy	Medium/high need	3	
Other: music therapy	Medium/high need	1	
Other: audiology	Medium/high need	1	
Other: nutritionist	Medium/high need	1	

## Military Family Needs

Over 88 % of military spouses reported at least one medium or high need for services for their family. Only a total of 15 military spouses indicated their family had no intervention needs at all. Respondents indicated a range of 1–7 ( $M = 3.15$ ,  $SD = 1.09$ ) family-level service needs. Military spouses reported respite care as the most frequent need (57.6 %). Another service military spouses reported their family needed was case management. Over half of respondents (53.1 %) indicated at least a medium level of need for case management services for their family. The military spouses were able to add any other family services or interventions they felt their family needed in the “Other” item response. Other interventions and services listed as at least a medium level of need were individual counseling, stress management, physical/occupational therapy, parent support groups, special needs legal help, and public awareness training. More information is provided in Table 3.

**Table 3** Military family needs

Item	Category	Frequency	Percentage
Case management	No/low need	83	46.9
	Medium/high need	94	53.1
	Total	177	
Family counseling	No/low need	119	67.2
	Medium/high need	58	32.7
	Total	177	
Family training	No/low need	100	56.2
	Medium/high need	78	43.8
	Total	178	
Respite care	No/low need	75	42.4
	Medium/high need	102	57.6
	Total	177	
Other: individual counseling	Medium/high need	1	
Other: stress management	Medium/high need	1	
Other: PT/OT	Medium/high need	1	
Other: parent support group	Medium/high need	1	
Other: special needs ADA legal	Medium/high need	1	
Other: public awareness training	Medium/high need	1	

## Discussion

Results indicated military families experienced difficulties related to intervention and service access, availability, quality, and frequency after relocation. This finding is significant because unlike civilian families who may be able to move to a location with better services or remain in the same area for the extent of their child with ASD's school years, military families do not choose their location and/or how often they move. Therefore, the difficulties experienced by families establishing intervention programs and services are compounded by the transitory nature of military life.

## Access

Most military spouses in the sample reported problems with accessibility, including not enough access to all the services their child with ASD required, delays in access to intervention, and limited access to assistive technology devices and services. Findings from this investigation support previous literature on military families with children with ASD, military families with children with special needs, and civilian families with children with ASD. Davis and Finke (2015) found military spouses reported limited service providers and delayed access to intervention as a result of moving. Government reports of military children with special needs found similar challenges with accessibility. Military families with a child with special needs reported problems finding a personal doctor and obtaining special therapies (Health Program Analysis and Evaluation Division, n.d.). Another report by the National Council on Disabilities (2011) found military spouses struggled for access to disability services and experienced gaps in services after relocating. Previous research with families of children with ASD has also reported accessibility issues in the civilian population. A systematic review by Tregnago and Cheak-Zamora (2012) indicated parents of children with ASD were more likely to experience difficulties with obtaining services and getting appointments and with delayed care than parents of children with other special needs. Similarly, Vohra et al. (2014) reported a greater number of

parents with children with ASD indicating problems with accessing services than parents of other developmental disabilities or mental health disorders.

### **Availability**

Finding medical interventions, finding providers who take Tricare, and the proximity of providers who take Tricare were all reported to be challenges related to moving by the military spouses who participated in the current study. This finding supports results from Davis and Finke (2015) suggesting service availability after relocation is an issue for military families with children with ASD. The military spouses in Davis and Finke (2015) reported limited providers in their area, needing to drive long distances to access the services their child needed, and the difficulty associated with starting over and finding new services every time they moved. Similarly, several government reports (NCD 2011; Health Program Analysis and Evaluation Division, no date) have reported on the challenges military spouses experience finding new providers each time they relocated. This was especially true when multiple providers were involved, and when services had limited availability in their new location. Civilian parents of children with ASD have also reported limited availability of clinicians who are trained in ASD (Brookman-Frazee et al. 2012).

### **Quality**

Respondents in this survey reported difficulties with the quality of interventions provided to their child with ASD after relocation. Most military spouses in the current study indicated the continuity of interventions was inadequate, dissatisfaction with the continuity of IEP/504 plans and quality of school interventions, and regression of intervention progress for their child following relocation. Results from this study supported previous research with military families with children with ASD and other special needs, military families without children with special needs, and civilian families with children with ASD.

Military parents with children with ASD have reported lack of intervention continuity, delayed therapy effectiveness, and lack of service quality by schools or other providers after relocating (Davis and Finke 2015). Similarly, government reports of military families with children with special needs have reported lack of uniformity of services in communities, schools, and bases between locations (NCD 2011) and discontinuity of health care and changes in treatment plans and IEPs (NCD 2011; Health Program Analysis and Evaluation Division, no date). Additionally, these reports also reported delayed progress after moving to a new location (NCD 2011). Further, frustration with discontinuity has been found in military families with children who are gifted or in accelerated education programs (Plucker and Yecke 1999) and children who are typically developing (Jelleyman and Spencer 2008). Although civilian families with children with ASD do not move as frequently as military families, many still report worries about transitioning between schools (Parsons et al. 2009) and feeling like their child is making slow progress (Brookman-Frazee et al. 2012).

Both military and civilian families with children with ASD have reported issues of intervention quality. Military families may have even greater challenges overcoming them, however, as the frequency of relocations results in military families working with many schools with different

eligibility criteria and therapists who implement different treatments. Further, some military families have reported feeling the school is not providing appropriate service because they are biding their time until the family moves again (NCD 2011). Military families also feel they do not have enough time to engage in due process in these circumstances to change their child's situation (Davis and Finke 2015).

## **Frequency**

The majority of military spouses reported not being satisfied with the frequency of interventions and services after relocation. Although frequency was not a factor listed by the participants in Davis and Finke (2015) or in government reports regarding military families with children with special needs, it has been recognized as a factor by civilian parents of children with ASD (Dymond et al. 2007).

## **Military Child Intervention Needs**

All military spouses reported at least one current intervention or service need for their oldest child with ASD ( $M = 5.84$ ; range = 1–10). The most common needs mentioned by the military spouses were social skills therapy, behavioral management intervention, speech-language therapy, and physical/occupational therapy. These findings are corroborated by previous research with families of children with ASD. Farmer et al. (2014) indicated 98.9 % of parents in their study reported at least one service need ( $M = 1.66$ ; range = 0–7). Some of the common needs were similar as well. Parents most commonly reported needing behavioral therapy, communication aids/devices, physical/occupational therapy, speech therapy, and mental health services (Farmer et al. 2014). The spouses in the current study reported four more needs on average than the civilian parents (Farmer et al. 2014). One possibility for this discrepancy is the difference in the number and type of services listed as responses for participants to choose from. Another possibility is the difference in how need was calculated. Another possibility is that military families with children with ASD have more unmet service needs than civilian families because their location and transitory lifestyle requires parents to frequently establish new intervention programs and navigate new systems of care.

## **Military Family Intervention Needs**

The majority of military spouses (88 %) indicated at least one current intervention need for their family ( $M = 3.15$ ; range = 1–7). Families stated the following needs in order from most to least common: respite care, case management, family training, and family counseling. Results were supported by previous research with civilian parents of children with ASD. In Farmer et al. (2014), family support needs were reported by 64 % of parents ( $M = 1$ ; range = 0–3). Parents also reported similar specific needs including respite care and family mental health (Farmer et al. 2014). Military spouses in the current study did not indicate the need for genetic counseling like civilian parents in Farmer et al. (2014); however, this was not a service specifically listed in the survey. As with the children with ASD, the military spouses reported more service needs on average and a larger range of needs than the parents did in Farmer et al. (2014). The needs of military families may be greater due to increased stress of the military lifestyle (e.g., relocation,

deployment), challenges related to finding establishing and maintaining services for their child with ASD, or differences in the surveys.

## **Implications**

The military spouses in this investigation indicated several barriers when describing their service delivery experiences. Many respondents reported difficulty accessing needed interventions, limited availability and proximity of providers, lack of continuity among service plans, and unsatisfactory quality of school interventions. Although reducing relocations may not be a feasible option because they are required for the mission of the DoD, establishing and/or modifying some existing supports may address the breadth of barriers reported by these military spouses. For example, a support that may address several issues is telehealth interventions. Telehealth interventions have the potential to increase availability and accessibility of services and clinicians while limiting proximity and continuity concerns.

Reducing more specific barriers, however, may necessitate putting new supports in place for these military families. Among the 11 service delivery experiences, five experiences were reported to be barriers by at least 60 % of military spouses and three of those were related to access. This indicated accessing interventions for their child with ASD was likely the most challenging service delivery category for military spouses; therefore, targeting access barriers may be an effective starting place for improving service delivery to military families. One support that could be established to help reduce access barriers and facilitate finding interventions may be a military-spouse mentor program. This program would link families with a child with ASD at a base with other families with children with ASD who are relocating to that base. The mentor could assist the mentee in finding providers and navigating the new community and school system. Another support for reducing barriers to finding services may be an up-to-date online resource for military parents to help locate providers in their area who accept Tricare.

Further, military spouses with children with ASD reported dissatisfaction with IEP continuity and quality of school interventions. Establishing a PCS protocol outlining responsibilities for the military family, as well as for the old school and new school would streamline the transition and may increase parent perceptions of IEP continuity and quality. Compiling these resources into one parent-friendly, comprehensive website may help to facilitate military parents' ability to participate in these programs and utilize these supports to locate services, understand legal mandates, and better advocate for their child and family.

## **Limitations**

Although this study utilized many best-practice guidelines for survey development, some limitations may affect the generalizability of the results of the survey. First, respondents were a self-selected convenience sample, not a randomized sample of the population; therefore, the respondents may not be representative of the entire military population of families with children with ASD. For example, military spouses who were dissatisfied with their experiences after relocation may have been more likely to take the survey to express their dissatisfaction; whereas, military spouses who were neutral may not have committed the time for the survey. Similarly, the sample may have demographic characteristics that differ from the population of military



families. However, it should be noted that several demographic characteristics were similar when comparing the sample to a recent DoD population survey (Military Community and Family Policy 2013). Also, even though this sample (N = 189) was larger than Davis and Finke's (2015) sample of military families with children with ASD (N = 15), it was still only a percentage of the entire population.

Second, the survey was limited to a specific population. Active duty military spouses may have a different experience or perspective than other stakeholders (e.g., military service members) or Reserve and National Guard families. Additionally, the ASD diagnosis status of the military children was not verified. In an attempt to reduce fabrication of diagnostic status, the survey was open to military spouses who had a child with any developmental disability. Also, military spouses who did not have a child with special needs would not likely be able to answer some of the survey questions specific to information and programs for military families with children with special needs.

Third, due to the online, self-administration nature of the survey, respondents were not able to ask questions regarding the survey content. It is possible respondents answered in a way they thought was appropriate for the question, but was not compatible with the researcher's intent. To decrease the effect of this limitation, a pilot test with members of the target population was conducted and noted ambiguities were corrected.

## **Future Research**

Research in this area should elaborate on the findings and address the limitations of this investigation. Although several service delivery experiences were reported to be challenging, it is not clear what part of the service delivery process is breaking down. Some respondents did not indicate difficulty with all service delivery experiences, while others did. This suggests there may be locations or situations where the supports in place are adequate to assist military families in particular aspects of service delivery. Future research should investigate what supports are currently successful, what supports need to be modified, and what supports need to be established. Based on the findings of these future studies, programs and supports should be developed to help address gaps in coverage for military families.

Additional research should gather perspectives from multiple stakeholders to describe a better, clearer picture of met and unmet service needs for military children with ASD and their families. Military service members may have different needs than their spouses because of deployment or separation from the family. Other important perspectives may be military leaders, Tricare or EFMP personnel, and medical and educational service providers. Researchers should also include other military populations, such as Reserve and National Guard families, and other disability populations, such as Down's syndrome, as these populations may experience related or different needs and supports than active duty families with children with ASD.

## **Conclusion**

The purpose of this study was to determine the service delivery experiences after relocation and intervention needs of military families with children with ASD. Results from this survey of 189

military spouses confirmed some of the barriers to ASD related services after relocation reported by participants in a previous peer-reviewed study (Davis and Finke 2015). While difficulties with intervention and service availability are not limited to military families, military families may be at additional risk because of the frequency of relocations and how often they must re-establish services. Most civilian families are able to stay in one location, or have the choice to stay in the same location and may only need to find new services and interventions upon receipt of the diagnosis or after a developmental transition; however, military families must go through this process every 2–3 years. This study was an important step in understanding some of the barriers associated with service delivery after relocation, a defining characteristic of the military lifestyle, for military families and their children with ASD.

## **Acknowledgments**

We would like to thank all of the families who graciously gave their time to participate in the survey and the groups and families who helped forward our recruiting message. Additionally, we would like to thank colleagues, friends, and family who offered guidance and support through the duration of this project. Thank you for your help and support.

## **Author Contributions**

JD conceived of the study, participated in its design and coordination, data collection, data analysis, and drafted the manuscript; EF participated in the design, data analysis, and manuscript revisions; BH participated in the design, statistical data analysis, and manuscript revisions. All authors read and approved the final manuscript.

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